

# POLIO NETWORK NEWS

**International Polio Network**

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**G.I.N.I.**

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Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

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## Underventilation: A Warning

WARNING to all who were weaned from an iron lung back in the 1950's. If you have trouble sleeping, morning headaches, and feel tired and unjoyous, show this article to your physician.

By Richard L. Weiler, Columbia, MO  
(Polio survivor)

Central Alveolar Hypoventilation Syndrome - my doctor's description of a condition which was slowly destroying me and of which I was alarmingly ignorant.

I am a polio survivor (1955) who relied on mechanical ventilation for approximately a year after the disease struck, six weeks in an iron lung and the remainder of the time in a chest cuirass or shell and a rocking bed. After this, it was decided that I could breathe adequately without mechanical ventilation and, at the age of sixteen, I began to cope with the severe paralysis which remained, a process which has taken a lifetime.

After six months at the Georgia Warm Springs Foundation, I returned home to Nebraska to complete high school. After that, college and law school at the University of Missouri, Columbia. Since 1968, I have been employed by the State of Missouri, currently with the Attorney General's office.

It is hard to remember when the first symptoms of breathing difficulties began to appear, but it was well before any public discussion of "post-polio syndrome." I began to experience difficulty in sleeping at night, I started having vivid dreams and sometimes nightmares, and I seemed to wake up often. This, of course, led to fatigue during the day.

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## Underventilation: A Warning

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Six years ago, my local doctor became concerned about continued high blood pressure readings and I started taking blood pressure medication. Approximately four years ago, I woke up in the middle of the night with a tremendous ache in my chest and stabbing pains down the left arm. Fearing a heart attack, I was rushed into the emergency room of the local hospital. Tests disclosed no damage to the heart but my breathing difficulties at night were noticed. Upon my physician's advice, I started using the chest cuirass or shell for breathing assistance at night.

Although the chest shell provided some relief for the next several years, the problem started accumulating again. My sleep patterns became very erratic (I would sleep heavily for an hour or two and then spend the rest of the night awake or in a shallow dream stage), I had morning headaches, tiredness during the day (at times I could not keep my eyes open), and at times I was not mentally alert. Sinus conditions from allergies aggravated the condition and made life miserable. At times I would be so tired at the end of the day that I could barely speak audibly.

Finally, in the fall of 1987, a doctor suggested a sleep test. Results indicated that the symptoms were caused by a carbon dioxide buildup because of inadequate ventilation at night. The doctor recommended a return to the iron lung at night. He suggested that daytime use might be necessary also in the future.

This was a real shock for me. My health had reached a point where continued employment seemed in jeopardy. Now the doctor was telling me that the cure might also make it impossible to continue employment. I decided to seek a second opinion from someone more knowledgeable on post-polio prob-

lems. After soliciting information from various sources available to me, I decided to contact Dr. Oscar Schwartz, a pulmonologist in St. Louis. Dr. Schwartz called me to discuss my condition and followed up with a letter. As a result, I checked into a hospital in St. Louis in early December, 1987.

I have heard weight lifters say "no pain, no gain." That describes my five day stay in the hospital under the supervision of Dr. Schwartz. They took so many blood samples that I think I am qualified for a Red Cross pin. I was introduced to positive pressure ventilation using a nasal mask which promptly blistered my nose. However, the gain was tremendous. The first night I used the nasal mask and positive pressure, I slept better than I had in years. By the end of five days the nasal mask no longer felt alien and I was sleeping soundly through the entire night.

I now wake up in the morning refreshed with plenty of stamina for the entire day. The morning headaches have receded and the periods of mental fatigue have disappeared.

The change has been obvious to all those around me. For the first time in a long time, I am enjoying myself both at home and at work. Even the blood pressure problems have disappeared. After evaluating the situation, Dr. Schwartz discontinued all of the blood pressure medicine.

Any polio survivor who required ventilatory support in the past, or whose current ventilation system is not allowing sound sleep, should seek the advice of a knowledgeable medical specialist. If you are not sure who that might be, Gini Laurie at International Polio Network will provide you with the necessary information.

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